



Rett Syndrome Europe

Summary Activity Report for General Assembly 27th November 2021

Full presentation at the General Assembly

We very much look forward to sharing more detail about our activities and discussing future plans with you at the meeting on 27th November 2021. Please do join the meeting to make this as productive as possible. Below are the key activities from 2021:

Formation of New Board

Four new board members – Becky Jenner, Laura Kanapieniene, Bojana Milanova, Sandrine Eifermann-Soutarson plus delighted to retain the knowledge and experience of Stella Peckary.

Designating specific roles and responsibilities – Becky Jenner – President, Stella Peckary – Treasurer, Laura Kanapieniene – Secretary

Reviewing Policies and Procedures

Reaching out to our membership

- Survey to members
- Recruiting volunteers
- Analysing and reporting on results
- You wanted improved communications and content on Website and Facebook
- More support for research across Europe

Launched E Newsletter as part of reinvigorating and improving communications.

- New regular features

Rett Resource

- Additional languages added
- More to follow

Reviewed and refreshed website – more to do on this

Networking –

- Global Rett Leaders Forum
- Rett UK presentation at their Virtual Family Roadshow
- November 11 Swiss Event
- Eurordis

Formation of Scientific Advisory Board

- Purpose
- Terms of reference
- Recruiting members
- First tasks: FAQs, Bios – video introductions, key research articles and articles written in layman's terms

October Awareness Campaign 2021 – A Life Worth Living

RSE Financial Report for 2020 signed by the auditor E.Nimmerrichter for information is attached